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Caring for people with bleeding disorders GRO-D

for info.

NQH 23/1/11

File

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Interesting. Ack 5/9

Yes

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No of Pages 6
FAX **Post-it®** Fax Note
Ref No: 7688

August 2000

(3) HCV file.

GRO-C 1/8.

Dear friend

THE HEPATITIS CAMPAIGN – TELL US YOUR VIEWS

I am writing to ask you to contribute your views to a strategic review of the Haemophilia Society's campaign on behalf of people with haemophilia who were infected with hepatitis C (HCV) through contaminated blood products. Having fought this campaign for more than six years under both a Conservative and a Labour government, the Trustee Board of the Society is now undertaking a full review of the HCV campaign, its aims and objectives, including an examination of what has been achieved so far and what the prospects may be for the future.

You will be aware that in July 1998 the then Health Secretary Frank Dobson MP rejected the Society's appeal for financial assistance to be provided to those affected by HCV within the haemophilia community. Immediately following that decision, the Board reviewed the campaign and decided to continue it. The aims of the campaign were subsequently developed to encompass the call for a public inquiry into the overall impact of contaminated blood products (i.e. both HIV and HCV) as has happened in Canada or Ireland. Four key aims for the campaign were also agreed as follows:

- To persuade Government to provide financial assistance to meet the needs of people with haemophilia or related bleeding disorders infected with HCV.
- To keep the issues of HCV infection through contaminated blood products high on the public and political agenda.
- To press for best treatment for people with haemophilia and related bleeding disorders infected with HCV.
- To raise public and political awareness of HCV.

Best treatment for all...

may be helpful to Minister's press statement 14/9

The context for the review is that the Society as a charity has limited resources. Therefore staff time/money devoted to the HCV campaign cannot be directed to meeting the increasing demand for our information, advice and support services – or for campaigning on other issues, such as recombinant. The Society's Trustee Board is responsible for the overall future direction of the charity, and so will need to make decisions about priorities and how best to allocate resources to meet the needs of people with haemophilia and related bleeding disorders.

I am aware that this campaign arouses very strong feelings within the haemophilia community, particularly around the matter of financial assistance.

Please take part in this important consultation by letting us know your views via the enclosed questionnaire. We want to have full input from all sections of the haemophilia community and all interested parties to assist the trustees' discussion of the future of this campaign.

The questionnaire needs to returned in the freepost envelope provided as soon as possible and **by Friday September 8 at the latest.**

Many thanks for your co-operation.

Yours sincerely

GRO-C

Karin Pappenheim
Chief Executive

Enc

Circulation List

- Members of the Haemophilia Society
- Members of the Medical Advisory Panel
- Chair of UKHCDO
- Chair of Haemophilia Nurses Association
- Chairs of Haemophilia Society local groups
- President and Vice Presidents of the Society
- Selection of MPs and MSPs
- Macfarlane Trust